Public Consultation on the draft Service Concept: Summary Report

An overview of the feedback and core considerations

September 2016 | FINAL

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INTRODUCTION

In recognition of the need to support and sustain the vital work of unpaid carers, in May 2015 the Australian Government committed to the development of an Integrated Plan for Carer Support Services (the Plan). The Plan includes two key stages.

The first stage of the Plan was the design and implementation of Carer Gateway, established to provide a recognisable source of clear, consistent and reliable information to help carers navigate the system of support and services. Carer Gateway commenced in December 2015 and includes a national website and phone service providing carer-specific information.

The second stage of the Plan involves the design of a new integrated carer support service system. The purpose of new service is to deliver supports that reduce caregiver strain with the twofold objective of increasing a carer's well-being and reducing the risk of the caring role ending.

The design of the new service will form the basis of a proposal to Government, for consideration on a new future integrated carer support service.

The first step in designing a new integrated carer support service was the development of a draft Service Concept which was released publically for comment from 2 May 2016 to 16 June 2016.

This report outlines the main feedback and themes captured through the 128 submissions received from a mix of carers, service providers, peak bodies and other Government departments.

A word of thanks

The Department of Social Services (DSS) would like to thank all who responded to the draft Service Concept consultation paper - it is essential that the design of future integrated carer support service continues to be a co-design process and informed by a broad range of perspectives.

About this document

This report has five main parts:

- About the Consultation: an overview of the consultation process, the number of responses received and feedback provided on the process.
- Carer Perspectives: an overview of the feedback received from carers.
- Overarching Themes: an overview of the feedback received from carers, service providers, peak bodies and other organisations, on the service design direction and process.
- Feedback on Specific Services: an overview of the feedback received regarding the proposed services.
- Features of a Future Service: an overview of the feedback received regarding the features and structure of a future service.

ABOUT THE PUBLIC CONSULTATION

The public consultation was conducted through the DSS Engage website. This website allows the submission of comments and documents through a secure portal.

The process also included the option to have a submission made publically available on the DSS Engage website. For this reason, not all of the submissions received have been made publically available. To view the publically available submissions, visit www.engage.dss.gov.au.

Submissions received

A total of 128 submissions were received as part of the public consultation process. The majority of submissions were received from service providers (51%) and carers (31%).

Submissions were also received from peak body organisations (8%), other government departments (5%), other individuals and institutions (5%) and care recipients (1%).

Feedback on the consultation process
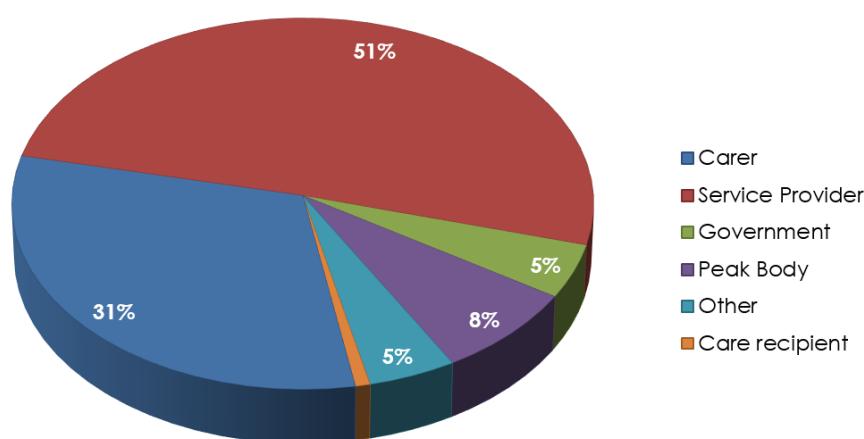
Service providers and other organisations found the document to be comprehensive in terms of its content and layout. Feedback from carers and other members of the public was that the document was long and written in a way that was sometimes hard to understand.

DSS will aim to provide shorter more concise documents that are inclusive of content and language suitable for both the sector and the general public.

CARER PERSPECTIVES

Feedback from carers in relation to the proposed services and their features are discussed within the relevant sections of this document. While in many cases there was similarity between carer feedback and that received from organisations, there were a number of core themes that were emphasised by carers.

Support to continue in employment

The strongest feedback received from carers was in relation to support to continue to participate in the workforce. Many highlighted the challenges faced in having to give up gainful employment in order to continue their caring role, resulting in significant financial strain and a loss of identity. Carers were seeking access to respite support services in order to continue their employment. Long day care respite was specifically mentioned, although some carers outlined that they required more flexible respite support to better meet the needs of their individual circumstances.

Support to transition back into employment

There were significant concerns expressed by carers in relation to obtaining access to education or training to enable them to return to the workforce, when their caring role changes or ends. Many carers considered this integral to their future security and well-being. Some carers outlined their efforts to engage in education to prepare themselves for this transition; however, a lack of flexible arrangements or difficulty in meeting vocational requirements posed a barrier for many. In provider responses, there were suggestions that some of the skills and experience carers gain while caring could be recognised towards certifications, particularly in paid caregiving roles, should they wish to pursue this career path.

Long-term financial outcomes

A number of carers highlighted that, in addition to the difficulties in sustaining or returning to the workforce, they were also disadvantaged in their long-term financial outcomes, particularly for those who spent a long period of time out of the paid workforce. The inability to participate in the workforce means, for those carers, they may have little or no superannuation.

Several carers also outlined they had difficulty in accessing financial loans. This was related to issues around eligibility for general loans or no/low interest loan schemes. Suggestions in relation to improving long-term financial outcomes included:

- allowing carers to earn more, while still receiving carer-related income support payments through Centrelink. Currently, carers receiving the Carer Payment are able to participate in work, including volunteer work, study or training for up to 25 hours per week, including travel time. Where carers exceed this, the payment they receive

may be affected. This limit was viewed by carers as a disincentive to return to work and improve their financial outcomes;

- better access to no or low interest loan schemes through government or other bodies; and
- providing tax benefits for carers to encourage people to take on caring roles.

Challenges relating to getting financial support today

Carers and service providers raised concerns in relation to obtaining financial support through Centrelink. Most comments related to challenges with the assessment criteria and process applied to determine eligibility for the Carer Allowance and Carer Payment. Difficulties included:

- interpreting the activities of daily living and how these are applied to the help carers provide to the person being cared for;
- meeting eligibility requirements when there is a long period required to reach a diagnosis for the person being cared for; and
- meeting eligibility requirements where the condition of the person being cared for is rare and not identified on the standard list of eligible diagnoses for payments.

The need for carers to be involved in service delivery

Feedback received from carers included a strong desire for carers, or people with past experience as a carer, to work within a future service. This was a view shared by the sector, with numerous organisations citing the benefits of using a peer-based support model, including enhanced rapport with support workers, improved information exchange and minimisation of stigma that may be associated with being a carer. Providers also highlighted that the use of a peer-based workforce was an effective way of reaching carers in Aboriginal and/or Torres Strait Islander and Culturally and Linguistically Diverse (CALD) communities.

Access to support for the person they care for

Many submissions from carers indicated they had difficulty accessing support for the person they care for. This included problems regarding availability or eligibility, or was related to the cost of paying for care. Several carers indicated they were awaiting the introduction of the National Disability Insurance Scheme (NDIS) in their area, as they saw this as being able to assist with these types of challenges.

Respite Services

A strong theme in carer submissions was the need for improved access to respite services. Some feedback related to particular ways that respite could be delivered, while others cited the ability to have a break or go on a holiday as important to them. In many cases, carers were seeking the ability to go on a holiday with the person they care for.

Practical and Emotional Support

Almost all carers were seeking both practical and emotional support. There was a mix of perspectives in the responses as to the relative weighting of each. For example, some

carers indicated they would prefer more help at home rather than counselling or similar. However, numerous carers described feelings and emotions relating to stress, depression and anxiety in their submissions, and highlighted the need for support their own mental health and well-being.

In relation to practical help, carers thought that assistance to do some of their daily activities, such as cleaning or household administration, would alleviate their burden.

OVERARCHING THEMES

Design approach

There was overall support for the way the draft Service Concept had been developed, which relied upon the use of evidence drawn from literature, feedback from carers, peak bodies and providers who work with carers, and surveys of carer experiences and opinions. However, there were some views to the contrary:

- some carers felt there had not been enough involvement of carers in the co-design process;
- some providers suggested the need for carers who are currently 'hidden' to be surveyed; and
- a perceived lack of engagement with the mental health sector through the process.

Shifting towards earlier intervention

There was strong support for moving towards an early intervention approach to support carers. This opinion was shared by organisations and carers alike however, it was noted that this could be challenging, particularly in relation to 'hidden carers' who may not realise they are undertaking a caring role.

The need to define outcomes

There was the desire from many organisations to see the link between the proposed services and the desired outcomes within the draft Service Concept. It was suggested by a number of service providers that a framework be developed that outlines the benefits that are trying to be achieved through the model.

Further, it was highlighted that outcomes can be difficult to measure for carers, as their well-being, level of strain, etc. is so strongly influenced by the person they are caring for. For this reason, it was suggested that narrative and qualitative data collection is included in outcome monitoring.

Carers did not focus specifically on the need for the definition of outcomes for the model but expressed views on what is should achieve, commonly related to the challenges they

were facing (e.g. the need for them to be able to remain in the workforce, to avoid poor long term financial outcomes, etc.).

Definition of carers

Some responses indicated there was a lack of clarity regarding who is defined as a carer. The definition of a carer (as specified in the *Carer Recognition Act 2012)* is as follows:

(1) *A carer is an individual who provides personal care, support and assistance to another individual who needs it because that other individual:*
   (a) *has a disability; or*
   (b) *has a medical condition (including a terminal or chronic illness); or*
   (c) *has a mental illness; or*
   (d) *is frail and aged.*

The Act further states:

(3) *To avoid doubt, an individual is not a carer merely because he or she:*
   (a) *is the spouse, de facto partner, parent, child or other relative of an individual, or is the guardian of an individual; or*
   (b) *lives with an individual who requires care.*

The definition does not include foster carers or grandparents who are caring for a child. However, if the person provides the child with personal care, support and assistance because the child has a disability, mental health condition, chronic disease or terminal illness, they would be considered a carer.

A person is also not a carer if they only provide care, support or assistance either for payment, such as a care or support worker, or as a volunteer for an organisation, or as part of the requirements of a course of education or training.

Some submissions highlighted the challenges associated with the term carer. Feedback suggests this is particularly relevant when talking about Aboriginal and/or Torres Strait Islander people and people from Culturally and Linguistically Diverse backgrounds where the concept of being a carer is not well recognised.

Valuing and respecting carers

There was strong support for the acknowledgement of, and value placed on, carers in the document. Many organisations welcomed a focus on carers as consumers of support services in their own right, including a consumer-directed approach. Carers who responded expressed the difficulties faced in justifying their role, or having to prove their role, to access services by both government and healthcare organisations.

Some submissions went further, proposing the use of ensuring carer rights as part of the future model

The need for individualised support

The majority of respondents highlighted that supports for carers need to be individualised and relevant to their needs. Service providers, peak bodies and other government departments stressed it was important to recognise that a one-size-fits-all approach would not be appropriate. In their submissions, carers indicated they were looking for support which was relevant to their needs and not merely standardised services.

Thinking about carers needs over time

A number of submissions highlighted a need to consider the types of supports required by carers at different times of the caring journey. Engagement with carers and organisations undertaken by DSS has also identified that a carer's needs will change over time, and that carers may need to dip in and out of services. Carers have indicated that, at times, they are overwhelmed with information and may not always be ready to engage with supports until there is a need. The *Carer Lifecourse Framework* was referenced in a number of submissions by service providers.

The need to provide specialised support

Carers may have particular information and support needs depending on the circumstances (including health conditions) of the person they care for. It is not intended that a future integrated carer support service system replace the many existing specialist organisations who provide condition-specific support for carers.

Carer choice and participation

There was strong feedback from carers and providers regarding carer choice as part of the future model. The draft Service Concept proposed that some supports would be delivered together. Specifically, this consisted of mentoring, financial support and respite support – defined as multi component support. Evidence regarding the effectiveness of these supports suggests that by combining them, better outcomes can be achieved. However, providers strongly recommended that the delivery of these three services together not be mandatory, and that carers should also (where appropriate) be able to access these supports individually. These sentiments were echoed by carers.

The need for a family approach to support

Organisations, particularly service providers and peak bodies, raised the need for a family approach to support. It was raised that addressing carer needs often relates to the needs of others within a family or social circle. It was suggested that there should be the ability to choose whether supports could be allocated to a family or an individual carer.

Some responses reflected the intertwined nature of carers and the person they are caring for, and the importance of a holistic approach to planning carer supports. A number of providers went further in describing how they felt this should be operationalised, such as funding organisations working with the person being cared for such as NDIS, My Aged Care, Alzheimer's Australia, etc. to assess and deliver carer services accordingly.

Carer support within other systems

Organisations and carers expressed concerns about the support for carers available through the major service systems, including:

- difficulty accessing supports through My Aged Care and the Commonwealth Home Support Programme due to age limits applied to eligibility;
- difficulty accessing carer specific support through the NDIS.

Many organisations were concerned about the transition of carer support programs and funding to the NDIS (e.g. the Young Carer Program). They felt that this would reduce the support and benefits specifically for carers under these programs.

Further, service providers highlighted that this would also produce gaps, expressing concerns that there would be limited identification of carer needs within the other service systems. Some providers acknowledged the close relationship between carers and the person they care for. Within this context, they stressed it would be important for the future service to also consider what supports were available through the care recipient systems, which may provide benefits for carers.

FEEDBACK ON SPECIFIC SERVICES

Awareness

Carers, service providers, peak bodies and other government departments emphasised the need for awareness to be raised through integration with:

- the health sector, including general practitioners, hospitals and Public Health Networks; and
- Centrelink and other Government agencies, including the National Disability Insurance Agency and My Aged Care

There was strong support for awareness raising through the health sector from carers, service providers, peak bodies and other government departments. Some organisations and carers recommended that in order to raise awareness and improve the early identification of carers, files/records relating to care recipients should be linked with those of their carers. This was referenced in relation to health and hospital systems, as well as other support systems (e.g. My Aged Care). This linkage was identified as having a threefold benefit:

1. it would increase the likelihood that a carer would be identified, and receive support (if required);
2. assisting in understanding the scale of the growing carer population; and
3. provide opportunities for improved information sharing about carers.

While challenges were identified in relation to awareness raising within the health sector, the majority of organisations that responded felt it was important to do this. A low number of service providers felt this was incompatible with the medical model of care (i.e. focussed on the needs of the patient, rather than their broader support network). However, a number of service providers, peak bodies and government departments cited programs and strategies that have been effective in raising awareness.

It was emphasised in organisations' submissions, and a small number of carer submissions that an understanding of the local service system and the community is required to adequately raise awareness for carers, particularly Aboriginal and/or Torres Strait Islander carers and carers from a Culturally and Linguistically Diverse Background.

Some peak bodies and service providers also suggested that awareness raising should occur within workplaces to enable improved understanding of, and support for, carers to sustain their caring role.

Peak bodies and service providers also proposed using peer workers at key contact places, particularly at hospitals (through discharge and social work areas), to connect carers with support. Submissions referenced a number of programs where peer contact workers are being used, with positive results.

Providers and carers supported the use of a strongly promoted brand or entry point for carers to seek support from[1].

Organisations directed DSS to engage with the Department of Education to assist with this issue. Those supporting young carers today all identified the school environment as one of the best avenues to identify young carers.

Organisations recommended that there be two primary approaches to raising awareness of young carers including:

- identification in the health system, preferably at the time of diagnosis of the care recipient; and
- ensuring schools are adequately equipped to identify and support young carers.

There were other suggestions that young carers could be targeted through social media as this is more aligned with their behaviours and communication preferences.

Information

There was consensus between responses from peak bodies, service providers and organisations that information must be tailored to the carer's circumstances. This was related to the condition of the person they are caring for, what stage they are in their caring journey, and ensuring that the information is of benefit to the carer's specific need or request.

In many submissions from organisations, it was highlighted that information and education are often blurred concepts, with information being provided as part of education programmes. Of particular note was the delivery of information, as part of the needs identification and planning process, where a strong correlation can then exist between the information being provided and a carer's needs. Organisations stressed that information needs to be available through different means (e.g. telephone, online, etc.) for different carer cohorts.

In submissions from carers, they expressed the need for information to be from a trusted source with many outlining difficulties they had experienced in finding services in their area or about supports they required. There were some carer submissions which supported the delivery of information through multiple means (online, telephone, etc.), others did not address the service specifically.

Education

There was strong support for the inclusion of education within an early intervention model. Organisations emphasised that more than one delivery method would be required and

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[1] It should be noted that this was not necessarily support for a *single* point of entry.

recommended enabling both online and face to face provision of educational support. They cited the benefits of face to face education as being a way to provide valuable information, enabling peer sharing and support, as well as providing an opportunity for more specific advice on their needs.

Peak bodies, service providers and other government departments raised the many specialised education programmes available to carers in the community today, and the need to ensure that these programs remain available to meet the needs of different carers in the community. A number of these organisations supported the implementation of a 'course finder' or calendar where carers could view the courses available to them.

They also viewed the provision of respite as an important incentive for carers to participate in education. They stated that carers may otherwise be reluctant to engage in education or training without this support.

Few carers specifically addressed education. Some had accessed educational programs and found them highly valuable. It was clear from many of the comments carers made that any such activity could not be perceived as a burden or something they needed to undertake. Other related comments were that carers were seeking to access support through a means of their choosing (online, face to face, etc.).

It was posed in the draft Service Concept that online forms of education have the potential to reach a greater number of carers than just face to face delivery of education and training. Many organisations acknowledged the benefits which online education could offer for carers in terms of accessing specialised programs or accessing such programs at a time of their choosing, or where they may not be able to attend a face to face course.

It was clear from organisation submissions that in order to access to educational resources online, there will need to be appropriate formats available, such as a modular structure for a carer to progressively complete at a time of their choosing or include short videos. In addition, these resources would need to be delivered in easy to understand language and consider cultural sensitivities. The inclusion of peer stories within these was also suggested by providers. Organisations also indicated that carers may require access to suitable technology in order to access such resources.

Peer Support

Many submissions from carers included references to the significant support they had received through peer support groups, which were predominantly face-to-face.

There was strong feedback from organisations that peer support was a crucial support to be offered under the future model due to its benefits at an early stage in the caring journey, and on an ongoing basis.

Multiple models of peer support activities and programmes were suggested including:

- peer support groups, both informal and formal;
- peer support workers, who work with carers at key points of contact (as noted in awareness);
- peer retreats;
- peer mentoring programmes; and
- peer education activities.

Feedback was received that the delivery of supports under this model should include a workforce with lived experience or peers. There was strong feedback from both carers and organisations that peer support programs and groups should be available via multiple means.

Peer Support Groups

When referenced in the submissions, face-to-face peer support groups have two primary formats:

1. formalised peer support groups, which, at least to begin with, involve a formal facilitator and, in some cases, financial support to sustain attendance at the activities;
2. informal (self-managing) peer support groups, which enable social opportunities and natural network building between carers.

Concerns were raised by numerous providers about the sustainability of informal groups without some moderation and administrative support. It was the view of most organisations that support groups required effective moderation and facilitation.

There were suggestions that the effectiveness of peer support groups could be improved by delivering targeted training and information as part of the group's activities. Other providers outlined the respite like benefits for carers to engage in activities which did not relate directly to their caring role, such as art based activities.

Many organisations suggested the development of a standard peer leader education framework, to be made accessible through a website and in written formats. It was also highlighted that some carers may need access to respite in order to access peer support.

Retreats & Peer Support

A number of organisations referred to carer retreats as a way of providing peer support, coupled with respite and targeted information and resilience building strategies.

There was strong feedback from carers and a number of providers that carers should be entitled to a holiday, similar to that of other working Australians. However, some other organisations stressed that funding of any retreat style activity must be outcome focussed, and include delivery of supports to build capacity and resilience.

Online Peer Support

The benefits of online peer support were acknowledged in numerous submissions from carers and organisations, some referring to those run by Sane Australia. Many organisations highlighted the benefits of providing a platform for carers in similar circumstances to connect over long distances, for example where the carer is located in a rural or remote region, or where they are seeking contact with carers who belong to particular groups. In addition, numerous submissions suggested this as an appropriate way for young carers to interact and receive support.

Peak bodies and service providers emphasised that these would require moderation and appropriate governance to ensure they were safe and productive environments.

Peer Mentoring

Peer mentoring was raised by a number of providers and carers as being beneficial and delivering targeted specific advice, in a non-threatening and acceptable way for carers. A number of the programs described were similar to the coaching and mentoring support service identified in the draft Service Concept. Further discussion is provided under Mentoring and Coaching.

Intake

Intake was viewed in different ways, ranging from an identity registration process through to triage or screening. There was a strong view that intake, or a registration-style process, should only occur where a carer requires access to funded support services. Having said this, many organisations acknowledged that some information about a carer's circumstances would likely be required to adequately match them with appropriate services. For example, in order to co-ordinate effective peer support groups or face to face education programmes, information is required about the carer's circumstances to appropriately match them to the best program.

It was suggested by some organisations that intake be viewed as a stepped process, by which information is gradually collected and built upon as a carer requires access to more intensive supports. For example, a carer may register online to participate in a peer support forum with a limited set of information, but complete more information when they would like to engage in a face-to-face forum conducted by a local organisation.

Feedback from organisations indicated that a future service would need to ensure that intake was undertaken in a sensitive manner, without an immediate request for information. They stressed it is necessary to first build rapport and add value for the carer as part of the interaction, and explain the reason for capturing any information. Some providers felt the intake process through My Aged Care, which requires a telephone and subsequent face to face assessment, was a negative experience. They highlighted that any such process should not duplicate information collection when connecting a carer with

specialised supports. However, some providers advocated for using a similar model to My Aged Care to conduct eligibility testing and intake.

There was strong support from carers and organisations suggested that multiple channels are needed to facilitate intake. This includes online, telephone, or face-to-face for particular groups of carers. Organisations strongly emphasised the need for a 'no wrong door' approach, particularly for Aboriginal and Torres Strait Islander carers and carers with a CALD background.

The ability to register an emergency care plan was largely accepted; however, timing was considered critical. Organisations stressed that this should not be attempted during a crisis or at the first contact, and development of this should be up to the carer. Benefits were identified in relation to being able to access an emergency care plan nationwide; however, some providers cautioned that there may be many complexities such as the storage of care recipient information within a carer-focussed system, and issues regarding privacy and access to such a system.

Other submissions highlighted that the creation of an emergency care plan may be a complex undertaking, particularly where it is being created for a carer of someone with a mental health condition. Therefore, they suggested this may not be suitable at the time of intake.

Despite some concerns from a small number of organisations around privacy, many carers and providers were strongly supportive of broader information sharing across the service sector to prevent them from having to provide that information repeatedly.

Needs Identification and Planning Support

Organisations were broadly supportive of using goal-based assessment as part of the future model. They cautioned against using approaches which prescribed what support a carer required. Goal based assessment and planning was viewed as in keeping with the shift towards prevention and embedded wellness principles. It was supported for its ability to use carer goals as a way to determine the most appropriate formal and informal supports.

Another common theme from organisations was that goal based planning should be undertaken after any immediate issues the carer may be facing (such as an imminent crisis) be dealt with. In some circumstances, providers discussed needs identification and planning as two discrete processes.

Goal-based planning was largely considered to be beneficial for carers, irrespective of whether or not a package they would receive a multi-component support package as a result.

Organisations stressed the need for the use of standardised tools to support such a process, with many citing what they were currently using to assess carer strain or similar measures.

One provider did not think a standardised tool would be effective because of the variability in circumstances.

A low number of carers commented on needs identification and planning support. Those who did felt there was value in this support but wanted to ensure if focussed on their needs. However, there were many responses from carers which indicated they were looking for a flexible service that was responsive to *their* needs rather than simply a mechanism to direct them to standardised services.

Some providers suggested carer assessment and identification should be undertaken taken through an integrated approach with the NDIS and My Aged Care.There was overall support for the use of self-assessment and planning tools from both carers and organisations. Organisations emphasised the need for such tools to be easy to use and a number viewed self-assessment being an effective way to screen carers for their needs, prior to a more in-depth engagement with a qualified support worker. Numerous organisations also indicated the need to have the ability to access help when someone was not able to use the tool, or encountered difficulty while using it.

They also offered some cautions in relation to self-assessment and ensuring that it would not be seen as an additional requirement for carers to have to undertake in order to get the help they needed.

There were numerous suggestions that such a self-assessment tool could also be utilised to help carers determine what other supports are available and they may be eligible to access.

Emergency Respite

Emergency respite was viewed as essential by both the sector and carers. Carers and organisations emphasised that emergency respite is required on a 24 hour, seven day a week basis.

Organisations and a small number of carers stressed that funding for emergency respite would need to remain separate to any future carer financial support package to ensure that carers do not save the funds for such purposes and defeat the intent of the package.

Multi-component Support

Organisations viewed the prioritisation of carers for multi-component support to be challenging. Difficulties were identified in relation to predicting which carers would have the greatest need, particularly for those in the early stages of caring. They suggested factors which could be used to prioritise the allocation of these supports including:

- the level of strain the carer is experiencing;
- the nature and intensity of the caring role;
- whether the person is willing to continue their caring role;
- capacity to pay;

- urgency of the response required;
- the nature of condition of the person being cared for (episodic, ongoing);
- the number of people being cared for, or other dependents;
- the degree of formal and informal supports being received;
- whether the carer was in a rural/remote area; and
- the complexity of the carer's circumstances.

Financial Support

While the inclusion of Financial Support within the draft Service Concept was welcomed by carers and the sector, implementation challenges were highlighted. Some carers viewed the delivery of direct cash payments as liberating and enabling them to use the funds towards flexible supports. Conversely, other carers viewed any likely administration process that would be required, such as submitting receipts and expenditure, as a burden. This concern was also expressed by many service providers and peak bodies. It was highlighted too that such an activity would not be able to be undertaken by young carers who may receive this form of support. Literacy, education and cultural issues were also perceived as barriers for certain groups of carers.

Organisations suggested providing user friendly tools such as budget trackers to assist carers to track their package, but highlighted that this may not be sufficient for those with limited computer or literacy skills. Some suggestions were made to lower the administrative burden, through the use of the new cashless welfare card, or through the use of vouchers.

Issues around the use of the funds were also explored. Carers and Service Providers expressed concerns that the funds would largely be used towards supports for the person being cared for. They were also concerned that carers may save the funds for an emergency purpose. This was raised as a primary reason that emergency respite funding is required to be separate to any consumer directed package. Service providers highlighted that clear guidelines regarding the use of these funds would be required.

The alternative to direct cash payments is the delivery of a financial package that is administered by a provider, as directed by a carer, such as the existing Carer Directed Respite Care packages. A number of organisations highlighted that this may incur a high administrative cost to providers, depending on what is required as part of the package. Conversely, other organisations argued that it could be done cost effectively and did not see a barrier to continuing to use a brokerage model.

Many providers raised that the allocation of these packages may not reflect an appropriate response to the changing nature of caring. Cares who are caring for someone with an episodic illness may require intensive periods of support during acute phases of that person's care, and then require little or no ongoing support outside of these times.

There were also concerns from organisations that if a package was only for a relatively small amount of money, it may be unworkable to administer such a package.

There were suggestions from a number of providers that financial support could be delivered in tiers, with different amounts allocated to assist carers with different levels of need or risk factors.

Mentoring and Coaching

The concept of mentoring was met with mixed responses by carers and providers. This was commonly related to the idea that mentoring would be a mandatory support, when coupled with the financial support package. Some carers viewed mentoring as something which would be beneficial to them but wanted to ensure this would be a collaborative process. Other carers were not supportive of a coaching or mentoring service, expressing a need for more respite or practical assistance instead.

Carers and most organisations indicated that a mentoring service would be best delivered by a workforce that includes people with past or current experience as a carer. Organisations, in particular, felt that this would produce more effective outcomes and may encourage uptake. Several providers highlighted their successes with such programs. Some cautions were offered that there needs to be careful management of boundaries in any such relationship between carer and mentor.

There was strong opposition to a professional determining whether or not a carer required coaching as part of their package. Some peak bodies, service providers and carers had expressed concerns that this would produce a negative experience and indicated that participation should be solely at the choice of the carer.

The draft Service Concept posed a question on when mentoring would be best delivered for carers, considering the intent of the model to shift towards early intervention. Responses from organisations reflected a range of opinions, including when a carer first commences their role as a carer, through to when a carer feels they want to access this type of support. Comments reflected that suggesting this type of support at a time of crisis would not be appropriate, that it is first necessary to deal with the emergency at hand, then put in longer-term supports in the period afterwards. This may include coaching where the carer wishes to use this support.

Organisations also identified the potential that a carer may require follow-up after their initial mentoring programme or need to access this type of support more than once in their caring journey. This was identified as being particularly important during times of change, such as when the needs of the person they care for change significantly.

Respite Support

While the inclusion of respite support within the proposed model was welcomed, organisations were concerned that access to respite may be limited to those carers in receipt of a multi-component support package. The draft Service Concept specified that

planned respite services are available through other service systems, such as My Aged Care and NDIS, Service Providers viewed this structure as flawed. The prevailing view from both providers and carers was that respite (planned and unplanned) is a service for carers, rather than for care recipients. Organisations stressed that respite should enable a carer to engage in activities that are meaningful to them, not merely the undertaking of other tasks necessary to their role (e.g. shopping, paying bills, etc.). A number of organisations proposed it should therefore be part of a future integrated carer support service model.

Providers discussed the different forms of respite, particularly for different cohorts. A number of organisations working with Aboriginal and Torres Strait Islander communities outlined that spending time 'on country' was a form of respite more suitable for their needs, rather than a traditional residential or other facility setting.

In the format presented in the draft Service Concept, respite support, as part of the multi-component intervention service, was intended to provide carers with help and encouragement to access respite services. However, organisations indicated that there can be a significant resource burden attached to such an activity, with between 30 and 40 phone calls required to find an available respite place. Some organisations suggested implementing a booking system to enable carers to more easily access respite. However, some providers highlighted the challenges faced in delivering respite, including the inability to utilise their beds or places to maximum utility where there were last minute cancellations or gaps in bookings.

A number of peak bodies and service providers referred to the need for more flexible respite to be available, either through brokered responses or through a cashed out model. This view was shared by some carers as they believed more flexible or in-home respite would better suit their needs or because they had had negative experiences in facility based respite services and preferred other approaches.

Counselling

The proposal included counselling as a service and this was met with mixed responses from carers and providers. Some carers outlined the positive experiences they have had with counselling, and stressed its importance as a support for them. In contrast, there were others who viewed this service as being better placed within other service systems, such as the health care system.

Organisations, on the whole, were supportive for the inclusion of counselling in the future model. Some Service Providers and carers raised concerns that counselling is a term that holds significant negative associations. Many providers recommended not using the term at all in the future model to avoid the stigmatised association. Organisations stressed that counselling needed to be normalised and promoted as a way of sustaining and improving carer wellbeing.

Some providers challenged the concept of counselling, as delivered by a qualified counsellor, suggesting that more informal methods of counselling are more likely to attract carers and provide early intervention. However, it was acknowledged that there was a need for formalised counselling for some carers who require it.

There was support for the inclusion of online and telephone-based counselling services specifically for carers; however, some providers felt this would not always be appropriate for carers in particular cohorts or where there may be significant distress. In these instances, access to face-to-face counselling would still be required.

All organisations that responded to this proposed service made suggestions for alternative techniques to be used to support carers. Suggestions included narrative, behaviour and music therapy, Solution Oriented (Focussed) Therapy, Emotional Focussed Brief Theory, Relationship Counselling, Motivational Interviewing, Positive Psychology, Mindfulness and Interpersonal psychotherapy. There was consensus that it was important to include these additional techniques to match the needs of particular carers and their circumstances.

FEATURES OF A FUTURE SERVICE

Regional and local support

Carers and organisations highlighted the need to deliver services in different ways depending on the local or regional structure and environment. For example, carer support responses for a carer in crisis in the Pilbara region will likely be vastly different to that in inner Sydney.

Further, carers and organisations highlighted that the need to navigate through national single entry points for support and access to services is not a desired experience for carers. This is particularly the case where carers may be in crisis and in need of immediate, skilled local support. There were some comments from providers and a small number of carers that centralised contact centres, while providing a single point of contact, do not offer the best value for carers. The Carer Gateway was mentioned by providers as not being able to provide locally relevant information for them. An alternate model suggested by several providers was the use of regional hubs to connect carers with local supports.

Concerns were raised regarding the allocation of funding to regional or local bodies in the current landscape. Several organisations highlighted significant variation in service responses, with one suggestion this is linked to inequitable allocation of funding.

The new integrated carer support service should be connected with regional organisations to adequately work with partners in the community to support carers.

Services accessed through multiple means

A number of carers and providers raised the need to deliver services in different ways to adequately reach carers from different cohorts. As carers span across almost every age range, culture and location in Australia, a future service will need to ensure there are avenues to support appropriate to the circumstances.

Many submissions highlighted the appropriateness of interactions with the service would be important for its success. There was some commentary that the shift towards digital service delivery for some services could cause further social isolation and that ultimately benefits may be reduced. However, some carers and providers commented that there would be significant benefits in providing digital service delivery for carers who may wish to interact with the service in this way. The main caveat added was that there needed to be more than one way to access the services in the model.

Respondents raised suggestions for features of a future service including:

- no wrong door- the ability for carers to access future services through a channel of their choice (e.g. online, face-to-face, or telephone); and
- the ability for a carer's information/record to be shared, either through electronic exchanges or via a centralised database, to prevent carers from having to repeat their story.

Concerns regarding transition arrangements and current infrastructure

The draft Service Concept did not focus on the future infrastructure required to support the delivery of the services, or discuss how any transition towards a model would occur. However, a number of providers expressed concerns regarding the transition to a future service and the implementation process. Concerns were related to the potential procurement of new organisations to delivery services who may not be sufficiently experienced in carer support and with an understanding of the regional or local environment. Related feedback included that the removal of existing regional organisations, such as Commonwealth Respite and Carelink Centres (CRCC), would be detrimental to many of the carers accessing their support services through those organisations today.

In addition, organisations also raised that any such transition would need to be carefully communicated to carers to minimise confusion and ensure they were supported through the period of change. It was suggested that one way to minimise disruption as part of a transition would be to reuse the existing data holdings of current organisations such as CRCCs.

Some providers expressed concerns regarding the transition of funding from carer support programmes to the NDIS, including the Young Carer Programme. Their discussion was focussed on whether this would continue to benefit young carers, as it would rely upon the identification of the young carer as part of the programme, and would not benefit those carers of people who are not eligible for the NDIS.

There was also discussion from providers regarding the alignment of the NDIS Information, Linkages and Capacity building framework and other services being considered as part of the future integrated carer support service. It was highlighted that the two needed to be complementary and not produce an overlap, in order to be effective and minimise confusion for carers in where to go to seek assistance.

Issues relating to transition were not raised by carers in their submissions.

OTHER FEEDBACK

There were some points of feedback raised in the submissions by one or very few respondents.

These included:

- the gendered nature of caring and the suggestion that the Government should consider carer support from this perspective (carer), specifically that women are more disadvantaged;
- hospital record linking between family members, to improve tracing of genetic conditions (carer);
- commentary on the need for a flat tax structure (care recipient);
- support for forgotten Australians (carer);
- funding of playgroups for carers of children with disability as part of the carer support model (service provider);
- challenges regarding suitable accommodation for adult children with a disability where the carer is ageing and less able to provide a caring role;
- suggestion that funding for respite be redirected towards medical research to cure the primary conditions of the person being cared for (care recipient);
- not using the term 'young carer' as it places undue burden and issues around identity for the person involved, particularly siblings (carer, peak body); and
- suggestion that the integrated carer support service should consider facilitating services required by both carers and care recipients (service provider).

APPENDIX A: PUBLIC SUBMISSIONS

The table below provides a list of all submissions received where permission to publish the submission was given. These can be viewed at https://engage.dss.gov.au/designing-the-new-integrated-carer-support-service.

Respondent Type	Name
Carer	Melanie Kathleen Smith
Carer	Julie Couzens
Carer	Patricia Chan
Carer	Sue Waters
Service Provider	Metro Community Hub
Carer	June Wilkes
Carer	Jillene Delahunty
Carer	Bea Sochan
Carer	Bernadette Redford
Carer	Jo Higgins
Carer	Peter Bradley
Service Provider	Grow
Carer	Cheryal
Carer	Lydie
Carer	Kay Brooks
Service Provider	The Benevolent Society
Service Provider	Barwon Health Carer Support
Service Provider	Intereach
Service Provider	Suncare Community Services Ltd
Carer	Melanie Smith
Service Provider	Beulah
Carer	Angela Pressley
Service Provider	Western Sydney Local Health District
Service Provider	Northern Sydney Local Health District
Carer	Schizophrenia Fellowship
Carer	Christopher Morgan
Carer	Gippsland Carers Association Inc
Service Provider	Playgroups Australia
Service Provider	Sutherland Shire Carer Support Service Inc
Carer	Carers QLD
Service Provider	Carers Link Barossa and Districts Inc.
Service Provider	Carer Support
Service Provider	Mind Australia
Service Provider	United Synergies
Peak Body	Alzheimer's Australia
Care recipient	Adam Johnston (ADJ Consultancy Services)

Respondent Type	Name
Service Provider	Anglicare
Carer	Anita Geach-Bennell
Service Provider	Baptist Care NSW & ACT
Carer	Michelle
Service Provider	CRCC National Working Group, UnitingCare lifeAssist
Carer	Dr Kathryn Knight
Other	Department of Developmental Disability Neuropsychiatry, UNSW Australia
Service Provider	Mallee Family Care
Service Provider	Anglicare Victoria - St Luke's region
Service Provider	Anglicare Victoria, St Luke's region
Service Provider	ACNA (Access Care Network Australia)
Service Provider	Siblings Australia
Service Provider	Commonwealth Respite and Carelink Centre NSW/ACT State Managers Network
Carer	Melanie Gold
Carer	Gail
Service Provider	Aged & Community Services Australia
Carer	Lianne Brewin
Peak Body	Carers Australia
Peak Body	Syndromes Without A Name (SWAN) Australia
Carer	Melinda Spencer
Government	Victorian Gov Department of Health and Human Services
Service Provider	South Australian CRCC Consortium
Carer	Eva Paluska
Service Provider	CareWest Ltd
Service Provider	Anglicare SA
Carer	Stephany Durack
Service Provider	Interchange Illawarra Inc.
Government	Seniors Collaborative Action Project (Barossa Council)
Service Provider	Carer Support Network SA
Service Provider	Northside Community Forum
Service Provider	Southern Migrant and Refugee Centre
Service Provider	Mallee Family Care
Service Provider	Alzheimer's Australia NSW
Service Provider	Merri Health
Service Provider	National Disability Services
Peak Body	Carers NSW
Service Provider	NSW Community Care Forum

Respondent Type	Name
Service Provider	Barnardos Australia
Service Provider	Jewish Care (Victoria) Inc.
Service Provider	HelpingMinds
Other	Ellis Blaikie
Service Provider	On behalf of the Victorian Carer Services Network
Service Provider	FamilyCare
Service Provider	FamilyCare
Service Provider	Macarthur Disability Services
Other	The Australian Centre for Social Innovation
Service Provider	WA Country Health Service
Other	Australian Association of Gerontology
Other	Stroke Foundation
Peak Body	Tandem Inc
Service Provider	UnitingCare Wesley Bowden and Northern Carers Network
Peak Body	Children and Young People with Disability Australia
Service Provider	Schizophrenia Fellowship of NSW Inc.
Service Provider	Leading Age Services Australia Ltd
Service Provider	MI Fellowship